



SPINAL COURIER

The spinal cord disability information source for Arkansans since 1989

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www.spinalcord.ar.gov

VOTE – Feel the Power

By Jan Baker, Managing Attorney, Disability Rights Center

The November 4, 2008, general election is considered by many to be the most important election in our lifetime. Unfortunately, voters in Arkansas often face barriers when going to the polls to cast their vote.

In the 2000 general election, only 38.2% of voting-aged population (VAP) with disabilities in Arkansas voted. This low turnout was due in part to barriers voters with disabilities often face when trying to vote. Low turn out of people with disabilities means that our voices are not being heard by the



politicians. Politicians take issues seriously when they are supported by a large group of voters. There are 529,563 people with disabilities in Arkansas who are voting age. Your vote can make a difference.

Common problems experienced by voters with disabilities in Arkansas:

- Inaccessible polling places
- Voter challenged because of disability
- Poll workers, equipment, or other accommodation
- Non-traditional signatures questioned
- Refusal to allow voter to bring assistant of choice
- Refused or rushed assistance
- Attitudinal barriers

See **Vote** on page 3

What Do You Want to See on the ASCC Website and Message Board?

The Arkansas Spinal Cord Commission maintains a website and has recently established a message board for the use of clients, family members and health care professionals. We are in the process of modernizing the design of the website as well as adding new content.

We would like to hear from you about these two services. What would like to see included on the website or the message board? If you need to refresh your memory, visit the sites and then send us your comments.

The address of the website is www.spinalcord.ar.gov and the address of the message board is www.websitetoolbox.com/mb/ascc.

You may phone Thomas Farley with your comments at **501-296-1785** or **800-459-1517**; email your comments to tfarley@arspinalcord.org or mail in your comments to:

Website Comments
ASCC
1501 N. University, Suite 400
Little Rock, AR 72207

Thank you. We appreciate your input!

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SPINAL COURIER

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With Thanks

Donations this quarter from:

Ms. Elizabeth Cathcart

In Memory of John M. Lane III
**Fayetteville
Field Office Staff
Arkansas
Rehabilitation Services**

ASCC accepts tax-deductible donations. Contributions are used to assist our clients through purchases of equipment and educational resources.

To make a contribution, please contact ASCC at **501-296-1788** / **1-800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

**AR Spinal Cord Commission
1501 N. University, Suite 470
Little Rock, AR 72207**

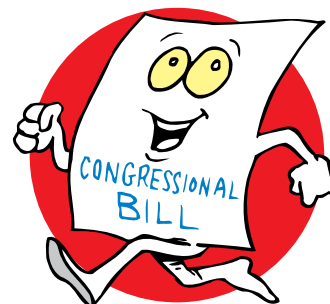
From the Director

As we move into the Fall of 2008, politics seems to be everywhere. You cannot turn on the TV or drive down the street without seeing advertisements for one candidate or another. Arkansans will also have some interesting decisions to make regarding constitutional amendments. At the national, state and local level, you can have a voice, if you just get out to vote. Many races over the past several years have been decided by a few hundred or, in some cases, a few individual votes. Your vote counts!

Unfortunately, no vote took place in the US Senate this summer on the Christopher and Dana Reeve Paralysis Act (CDRPA). The Act, S.1183 has been passed in the US House of Representatives twice, in 2006 and in 2007, and the Senate Health, Education, Labor and Pensions Committee, but has not come to a vote in the Senate, primarily due to the actions of one Senator (see what I mean about one person making a difference!).

The CDRPA has three components:

Title I. Paralysis Research expands paralysis research and promotes collaboration - connecting scientists doing similar work in multiple fields to speed discovery of better treatments and cures at the National Institutes of Health (NIH).



Title II. Paralysis Rehabilitation and Care calls for rehabilitation research to advance daily function for people with paralysis including intensive, activity-based research to measure the effectiveness of certain rehabilitative tactics that aim to improve mobility, prevent secondary complications, and develop improved assistive technology.

Title III. Improving Quality of Life for Persons with Paralysis and Other Physical Disabilities will develop unique programs at the Centers for Disease Control & Prevention (CDC) to better the quality of life and long-term health status of persons with paralysis and other physical disabilities. None sound very controversial to me!

Kudos to Senator Mark Pryor for working with Act sponsor Senator Tom Harkins to move the bill forward, through an omnibus act in July. Though both Senator Pryor and Senator Lincoln voted for the bill, they came up a few votes short and the bill did not pass. I'm certain that Senator Harkins will continue to forge on with the bill, but the Congress will adjourn for 2008 in just a few weeks. Without a vote, they will start all over again in 2009.

This fall, you have an opportunity to vote for the folks who will represent your interests. Don't miss your chance to vote!

For additional information on the CDRPA, go to
www.christopherreeve.org

Cheryl L. Vines

Spina Bifida Association News

The Spina Bifida Association of Arkansas (SBAAR) provides services to individuals with spina bifida and their families in Arkansas. ASCC and SBAAR work closely on many activities and programs.

- SBAAR is pleased to announce that a 2008 academic scholarship of \$1,000 has been awarded to Justin Bickel of North Little Rock. Justin is a student at the University of Central Arkansas and is studying accounting.

- Mark your calendars now for the Spina Bifida Association Annual Christmas Party. All individuals who live with spina bifida and their families are welcome. The party will be held at the Baring Cross Baptist Church Recreation Center, 7541 Warden Rd (next to Kohls) in Sherwood. Please note, this year's party will be on Saturday, December 13th from 2:00 to 4:00 p.m. Activities will include music, games, fellowship, refreshments and a visit from You Know Who!

- Julie Mayberry whose daughter Katie lives with spina bifida and who has long experience working with the media is passionate about the need for a resource for new parents.

She is working with the Spina Bifida Association of Arkansas to develop a DVD for new families to help them understand the joys and tribulations of life with spina bifida. At the Christmas party, Julie will be conducting interviews with individuals with spina bifida and parents who would like to share their experiences for the DVD. If you would be interested in doing an interview, please contact the SBA office at **501-978-SBAA** to schedule a time on the afternoon of the party.

- If you would like to join SBAAR, annual dues are \$20 per individual or family. Call **501-978-SBAA** for a membership application.

Wheelchair Basketball Team Forming in Springdale

A new wheelchair basketball team is organizing in Springdale and is actively seeking recruits. The "Wild Wheels" team currently has four players and is in need of more. The team meets on Wednesdays at 6:30 p.m. at the All Star Sports Arena on Robinson in Springdale.



The team is also seeking sponsors and equipment. If you are interested in joining the team or would like to help this team become established, contact **Craig Blanchard** at **479-586-0285** after 4:30 p.m. Any help would be appreciated!

Vote

Continued from page 1

HELP AMERICA VOTE ACT OF 2002 (HAVA) - was enacted to overhaul federal elections in the United States by mandating a new set of minimum voting standards for each state and territory. HAVA contains several provisions that will enable state and local units of government responsible for elections and individuals associated with operating the election process to establish, expand, and improve access to and participation in the election process by individuals with the full range of disabilities.

HAVA also requires states to have a grievance procedure for providing resolution of any complaint alleging a violation of any provision of Title III of HAVA, including a violation that has occurred, is occurring, or is

about to occur. For a copy of the Arkansas State Board of Election Commissioner's "Rules for HAVA Administrative Complaint Procedure," go to www.arkansas.gov/sbec/pdf/hava_final_rules.pdf

You can also contact Disability Rights Center (DRC) if you experience problems when you go to vote. DRC is the protection and advocacy system for people with disabilities in Arkansas. DRC is available to provide comprehensive advocacy services that will help prevent widespread disenfranchisement of voters with disabilities.

DRC is available to take complaints of voters with disabilities who are disenfranchised in the electoral process and assist voters who would like to file a complaint with the Arkansas State Board of Election Commissioners.

To contact DRC: Tel/TTY: **501-296-1775**; FAX: **501-296-1779**; Toll free: **1-800-482-1174** V/TTY

Also, take a look at DRC's voting and disabilities commercial entitled "Make Your Vote Count!" at <http://video.google.com/videoplay?docid=-2534511086531756603&hl=en>

With every election, fair-minded voters with disabilities have an opportunity to advance the rights of people with disabilities by supporting candidates who support equality. The key to voting access on November 4, 2008, will be knowledge. Voters with disabilities need to know their rights. October 6, 2008 is the voter registration deadline.

For more information on your voting rights go to **www.arkdisabilityrights.org**

The Scientific Data on SCI Regeneration: Where Do We Go From Here?

By Tom Kiser, M.D., ASCC Medical Director

Almost every clinic visit I have in my office these days involves a discussion of spinal cord injury regeneration and, eventually, whether or not it is wise to go to another country to seek treatment. The promises of a cure by the scientific and commercial entities involved in spinal cord injury regeneration have been loud and compelling, yet still we do not have any large human studies in the United States. Other international countries are allowing the use of stem cells and other treatment options, although usually at a cost to the patient in money, travel time, and health risks.

What should a SCI person do in light of all the promises and options available to them? My advice at the present time is—*wait*. Wait for a well designed study with compelling animal data from several labs and for a small pilot study in humans to show that the risks of the treatment are minimal.

The initial excitement and promise of a cure really began in 1981 when experiments showed that spinal axons could grow into a peripheral nerve but not back into the spinal cord. In 1988 further experiments showed that oligodendroglial cells expressed a factor that inhibits axon growth; this factor was isolated in 2000 by Chen and Huber et al., and called – “Nogo-A,” a potent inhibitor to nerve cell growth in the central nervous system. Since that time many positive reports have come from numerous animal studies in spinal cord regeneration and have been reported in the scientific and mass media with much fanfare and promise.

The problem is that the positives have been accentuated and the negatives have been downplayed.

Here are some of the negatives:

1. Animal data has limited power to predict clinical effects in human trials. Despite multiple successful animal experiments, only a few human trials have been initiated with, in general, disappointing results.
2. Preclinical (animal) data often cannot be reproduced in another lab trying to reproduce the same results, suggesting a problem of generalizability and repeatability of the study design.
3. Dramatic recovery with single agent therapy is very unlikely, and a combination of treatment strategies needs to be studied. Due to the complex nature of interactions and the unpredictability of sequential treatment strategies, this has not been an easy task.
4. It is unwise to overvalue initial positive studies and case reports from international studies. The information on new advancements in spinal cord injury from overseas is newsworthy and eye catching, but very short on details. It lacks critical peer review and is often first reported in the mass media.
5. Study outcomes only apply to the population studied (which to date have mostly been in rats with an acute spinal cord injury model).¹
6. To date we can get axons to regenerate by providing a bridge substrate, growth factors, and blocking inhibitory factors; the problem is that no growth beyond the graft site has been obtained.
7. Rodents do not need corticospinal tracts to improve function. So the initial animal studies do not provide a good model for potential treatment options in humans,



ASCC Medical Director Tom Kiser, M.D.

suggesting the need for repeatable outcomes in different labs with different animal models.²

Ronsyn, et al., derive the following conclusions in their review of the present literature on spinal cord injury regeneration: 1. “Although different treatment options have proven to be successful in animal models, they also provide a realistic view on a complex therapeutical approach, which needs to be further investigated in many carefully designed animal studies before human applications can be considered;” and 2. “...perfect restoration of the original anatomy of the spinal cord may not be the ultimate aim at the moment.”³

Wendell Berry in his critical analysis of science makes the following observations: “The only science we have or can have is **human** science; it has human limits and is involved always with human ignorance and human error; and the living world is larger and more complex than our works. Because we must be always correcting our errors, art and science always need to be free to shift their ground and start again.”⁴

So I encourage patience and waiting. The research and science is promising and encouraging, but the risks and benefits need to be better defined before I can recommend any of the overseas treatment options to someone with a spinal cord injury.

See **Scientific Data** on page 5

Support Group News and Activities

The three spinal cord disability support groups that meet in central Arkansas have made some changes in their meeting time and place to accomodate upcoming holiday season special events.

The Conway SALAD (Support After Life Altering Disabilities) group has changed their meetings to the **first Thursday of each month** from 1:00 p.m. to 2:00 p.m. at the Conway Public Library.

The White County Spinal Cord Injury Support Group, which usually meets the first Tuesday monthly from 10:30 a.m. to 12:00 noon at the White County Medical Center, Hubach Conference Room A, will be having a **Potluck at the Friendly Acres Park Pavilion in Judsonia on Tuesday, November 4th from 11:00 a.m. to 12:30 p.m.** Please call Dee Welsh at **501-296-1792 or 800-459-1517** to let her know how many are coming and the dish you plan to bring by Oct. 27, 2008. The December 2nd meeting will held in Dining Room A. The group does not meet in the months of January or July.

St. Vincent Rehabilitation Hospital Sherwood SCI Support Group, which meets the third Thursday monthly from **11:30 a.m. to 1:00 p.m.** in the Conference Room, will be having their **Thanksgiving Potluck on November 20, 2008.**

Scientific Data

Continued from page 4

1. Guest, J. (2008). *Manipulation of hope or cure in SCI by commercial entities*. Lecture presented at American Spinal Injury Association.
2. Tuszyski, M. (2008). *Enhancing plasticity, and regeneration after SCI: Challenge of clinical translation*. Lecture presented at American Spinal Injury Association.
3. Ronsyn, M.W., et al. (2008). Can cell therapy heal a spinal cord injury? *Spinal Cord*, 46, 532-539.
4. Berry, W. (2000). *Life is a Miracle: an essay against modern superstition*. New York, NY: Counterpoint.

WHEELCHAIR BASKETBALL SCHEDULE, 2008-2009

ARKANSAS ROLLIN' RAZORBACKS

September 13, 2008

Rollin' Razorbacks Demonstration, Russellville, AR

October 4, 2008

Arkansas Disability Coalition Demonstration, Sherwood, AR

October 11-12, 2008

Arkansas Valley Conference Preseason Tournament, Springdale, AR

November 8-9

Dallas Invitational, Dallas, TX

November 22, 2008

University of Alabama Invitational, Tuscaloosa, AL

December 13, 2008

Fort Smith Invitational, Fort Smith, AR

January 9-11, 2009

Pioneer Classic, Birmingham, AL

January 24-25, 2009

Oklahoma University Invitational, Norman, OK

January 31, 2009

Arkansas Valley Conference Tournament, Sherwood, AR
Teams: Tulsa, Fort Smith, Springdale, Rollin' Razorbacks

February 20-22

Las Vegas Invitational, Las Vegas, NV

February 27- March 1, 2009

NWBA Regional Tournament, TBA

March 20-21

NWBA Championship Division Tournament, Denver, CO

SHOOTIN' STARS SCHEDULE

October 10-11, 2008, Springdale, AR
Pre-Season Tournament (All teams)

December 13, 2008, Van Buren, AR
L.R., Tulsa, Springdale, Fort Smith

January 10, 2009, Tulsa, OK
Tulsa, Fort Smith, OU, Springdale, MAPVA

January 31, 2009, Sherwood, AR
L.R., OU, OSU, Fort Smith, Springdale

February 28, 2009, OSU University
Post-Season Tournament (All teams)

Up Close and Personal: Sandy Turner

This is the first in a series of articles profiling the ASCC Commissioners.



Sandy Turner was returning home to Little Rock from Easter holiday in Mississippi on April 3, 1994, when she was run off the road. She remembers little about the crash, but awoke with a T2 spinal cord injury, broken arm, and other injuries. She spent several weeks in intensive care and eventually went to Shepherd Spinal Center, at the recommendation of a close friend.

A year later, she was appointed to the Commission by Governor Jim Guy Tucker and reappointed in 2005 by Governor Huckabee.

Sandy brings a wealth of experience to the Commission. When she was injured, she was the producer of "Seven on Your Side," a consumer assistance program with a local television station. She has been involved in many community service organizations and activities in the state and early in her career worked for US Congressman Beryl Anthony in Washington DC.

Sandy was integral in the establishment of the Arkansas Spinal Cord Foundation (ASCF), a tax exempt, not-for-profit organization with a mission to improve the health and well being of Arkansans with spinal cord disabilities. She presently serves as Chairperson of ASCF.

Over the years, Sandy has provided peer support to individuals and

their families while dealing with her own secondary conditions. In her 14 years on the Commission, Sandy has seen many changes and accomplishments. "It is good to feel like you are helping other Arkansans with spinal cord disabilities," she says. "It is important to me to see how many people there are and what their needs are, so we can find ways to help."

ASCC is fortunate to have Sandy Turner on the Commission.

PROFILE:

Date And Place Of Birth: October 12 in Oxford, MS.

Family Members: Daughter Withers, 24 and Lilly the cat.

If I Did Not Live In Arkansas, I Would Want To Be: In New York City.

My Favorite Food Is: Tomatoes.

My Favorite Movie Is: *Gone with the Wind*.

Last Good Book I Read: *Become a Better You: Seven Keys to Improving Your Life Every Day* by Joel Osteen.

My Favorite Pastimes Are: Bridge, investment club, Colonial Varnes and movies.

The Best Advice I Ever Received Was: "Be positive."

My Advice to the Newly Injured: "Things WILL work out."

I Knew I Was Grown Up When: I had my wreck!

The One Thing I Always Wanted To Do But Have Never Had The Chance Was: Go on a safari.

One Word To Sum Me Up: Optimistic.

New Phone Number for ASCC Hot Springs Office

The ASCC office in Hot Springs has a new phone extension and a new direct line.

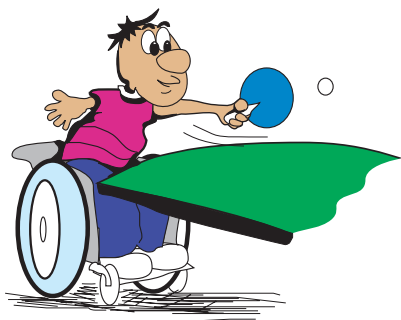
You can continue to call 501-624-4411 and the ext. 6591 or you can call the office direct by calling **501-701-6591**. The FAX number remains the same: 501-622-6623. Please make a note of the new number.

Doug Moore and Matthew Powell Medal at National Veterans Wheelchair Games

Quest for the Best—that was this year's motto at the 28th National Veterans Wheelchair Games held July 25-29 in Omaha, NE. What a great city! The weather might have been hot in Arkansas but it was just right in Omaha. Over 550 athletes from around the world came to Omaha to test their abilities in different sports.

This year Matthew Powell of Charleston, AR competed in power soccer, table tennis and bowling. He was able to bring home the bronze medal in bowling and table tennis.

Doug Moore of Van Buren, AR competed in softball, basketball, javelin throw, discus and shotput. He was fortunate to be able to bring home gold medals in softball, javelin throw and shotput and a silver medal in discus. Both had a great time.



The wheelchair games mean more to Matt and Doug than just winning medals. It is a special occasion they look forward to every year. A time to renew old friendships and make new ones; plus knowing they all have one thing in common—they all served their country.

Matt and Doug thank Mid-America PVA and NLR VA Medical Center for allowing them to attend this year's games and they are looking forward to next year. God bless our soldiers. For more information about the national Veterans Wheelchair games go to **pva.org**.



Jonna Bloodworth.



Barbara Davis.

New Support Staff Join Fort Smith and Fayetteville Offices

Jonna Kay Bloodworth recently became Maryanne Caldwell's secretary in the Fayetteville office and Barbara Davis was hired to be Kay Lynn's secretary in the Fort Smith office.

Jonna has worked in the same office as Maryanne for Arkansas Rehabilitation Services for the last five years as a receptionist. So, when she was hired to be Maryanne's secretary she just moved down the hall. Jonna has a family of 3 daughters, 5 grandchildren, and 1 dachshund. She loves to sew and do needle work. Jonna is the current Miss Wheelchair Arkansas and is thrilled with her title. She

has had the opportunity to travel to other parts of Arkansas and speak about disabilities.

Barbara is from Tulsa, OK where she was in retail management for over 20 years. She has a daughter age 27, a son age 22, and a granddaughter age 7. In July, she married Steve Davis and inherited two more daughters whose ages are 22 and 10. Barbara loves cooking, baking, scrapbooking, and spending time with her family—and she loves her new job!

Please join us in welcoming Jonna and Barbara to the Arkansas Spinal Cord Commission.

Get Your Flu Shot Now!

Dr. Thomas Kiser, ASCC Medical Director, recommends anyone with a spinal cord injury in the cervical region or high thoracic region (T6 and above) get a flu shot.

"Because of your weak cough and decrease in pulmonary reserves you need to have the maximum protection against the influenza virus," he said.

"I also recommend a pneumococcal vaccination to anyone with a spinal cord injury," he added. "You

can get it at the same time as your influenza vaccination."

Influenza is a highly infectious viral disease that occurs in winter months (October to March). "Flu season" usually begins in November, peaks in December and is usually over by March, but it can occur as early as October.

Call your doctor now to set up an appointment for your influenza vaccination and stay healthy this winter.



The Squeaky Wheel

The squeaky wheel . . . gets the grease! This column is about grease—things that make life for persons with spinal cord disability go smoother and ease your way in the world. “Things” can be hints, equipment adaptations, innovations, tricks-of-the-trade, procedural shortcuts, life experiences, or things you “should have done but didn’t.”

Dana Wolf of Gamaliel, AR tells us how he solved his problem of not drinking enough water and wound up inventing a device that may be of benefit to others.

I have been quadriplegic for 35 years. Physicians have told me people with spinal cord injuries should drink more water in order to flush their kidneys and keep them healthy.

A friend of mine just had a procedure to break up kidney stones that didn’t sound too pleasant. I, too, had kidney stones 30 years ago when I had to have them surgically removed—something I would like to avoid in the future. At the time of

my surgery, I did not drink enough water; the main reason I didn’t drink enough water was I had to empty my urinary leg bag often and there was no one around in school to assist me.

Since then, I have developed an electric leg bag emptier which allows me to empty my leg bag myself, increase my fluid intake, and avoid kidney stones.

The leg bag emptier I developed

activates with a push button that releases the electric valve that pinches the drainage bag tubing. It does not require cleaning because the urine never touches the valve.

I found this to be the best solution for me and others who have used it are very pleased with the results.

If you would like more information you can view the leg bag emptier on the internet at:

www.superquads.com.

We invite you to send in your helpful hint—your bit of “grease.” Contact your ASCC Case Manager, write us at *Spinal Courier*, Arkansas Spinal Cord Commission, 1501 N. University, Suite 400, Little Rock, AR 72207 or e-mail us at **courier@arspinalcord.org** and put “Squeaky Wheel” in the subject line.

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